



ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES

RESEARCH, EDUCATION, SERVICE

Written testimony

of

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For the

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Labor, Health and Human Services, Education Subcommittee

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Representing the

Association of University Centers on Disabilities (AUCD)
Silver Spring, Maryland

Mr. Chairman, on behalf of the Association of University Centers on Disabilities (AUCD), I am pleased to submit this written testimony for the record both as a means to thank you for the Committee's support of our Centers over the past several years, and as a way of alerting you to the exciting developments happening now across the national network of University Centers for Excellence in Developmental Disabilities, Education, Research and Service (UCEDDs). The network of UCEDDs is a showcase for unique and effective models for gathering new knowledge and developing approaches based on the best of what science has to offer in the field of developmental disabilities. The network of Centers serves as a means to share this knowledge both nationally and internationally, as well as in our own states to improve the lives of people with developmental and other disabilities. I am Lucille Zeph, Director of the Center for Community Inclusion and Disability Studies, Maine's University Center for Excellence in Developmental Disabilities at the University of Maine and currently serve as the President of the Board of Directors of AUCD.

The mission of the UCEDDs is to advance policy and practice, for and with people with developmental and other disabilities, their families and communities. As a network of 64 interdisciplinary Centers across the U.S. and its Territories, we work to ensure full participation in all aspects of living for individuals with disabilities.

Since the early 1960s, when Congress established a small number of research centers to study mental retardation, we have grown into a national network where each University Center has developed its own area(s) of expertise based on the needs of the local community, state, and evolving expectations of people with disabilities nationwide to be more included in community life. Authorized by the Developmental Disabilities Assistance and Bill of Rights Act (P.L. 106-402) we currently focus our work on serving as a national education and training, service and information resource and research entity for our nation.

The AUCD Network also supports a unique network of 35 Leadership Education in Neurodevelopmental Disabilities (LEND) interdisciplinary training programs. These programs are funded through the Maternal and Child Health Block Grant (Title V of the Social Security Act) and therefore, focus on children with, or at risk for, special health care needs/severe disabilities, especially the most vulnerable and underserved. The programs do a remarkable job in preparing highly skilled professional leaders, at the graduate level and through continuing education, to both provide comprehensive care to children with special health care needs and to improve the systems of care needed by these individuals and their families.

We are respectfully seeking an appropriation of \$37 million for the UCEDD network FY 2007. The additional resources for UCEDDs will allow for the establishment of four more Centers. We hope to establish two in states that have and continue to grow in population and diversity such as California and Georgia. For example there is no center in the northern half of California so that families must travel all the way to Los Angeles to obtain the services of a UCEDD. The resources will also allow for the establishment of two Centers at minority serving institutions of higher education. As our

country's demographics change we need to continue to diversify our professional workforce so that we can address the growing health disparities that are developing. In Mississippi, for example, the U.S. Census Bureau identifies 36.6 percent of the population as Black or African American. In Texas, 32 percent identify as Hispanic or of Latino origin. There are currently no Historically Black Colleges and Universities (HCBU) that are UCEDDS. We believe that having minority based institutions of higher learning would help to significantly increase the number of leaders from minority backgrounds in the field of developmental and related disabilities.

In addition, we are respectfully seeking an increase in funding that is specifically set aside for LEND programs within the SPRANS portion of the Title V Block Grant, to \$22, 677, 644. This program has been level funded for the last five years at \$18,677,644 from the Special Projects of Regional and National Significance (SPRANS) portion of the Title V Block Grant. Without additional funding the impact of the LEND network has been reduced and there is no possibility for expansion to provide needed training to developing professionals that serve people with disabilities in currently unserved and underserved areas.

The resources requested for the LEND program will provide for the training of professionals across an array of critical disciplines that will help this country meet the growing needs of children with autism and genetic disorders. As research continues to find answers to questions of how best to serve children with conditions such as autism and Down syndrome we will be desperately in need of appropriately trained professionals to translate the science into community and clinical practice.

AUCD believes that all people with disabilities must have the opportunity to maximize their potential, and have equal and meaningful access to all programs that help people be part of community life. We have been honored and pleased to work with President Bush and his Administration to carry out initiatives established in the New Freedom Initiative. Through Executive Order 12317, "Community-Based Alternatives for Individuals with Disabilities" we are working at the state and national levels to implement programs and secure funding to rebalance the system of care for individuals with disabilities and their families. We believe that the country is at a turning point that can truly change the way that individuals with disabilities are perceived, treated, and supported. By assisting states in their efforts to rebalance their service systems to serve people in the community, rather than in institutional settings, we are truly working to achieve the President's goals set forward in the Executive Order.

The UCEDDs focus their work in a concerted manner through the delivery of education and training at the university and community levels; the conduct of basic and applied research; and service provision at the individual and family level. Following are some examples in each of these areas.

Education – Quality of life in the community for individuals with disabilities depends upon well-trained professionals. Positioned within the university, UCEDDs educate the next cohort of professionals in interdisciplinary approaches and provide continuing

education for professionals practicing in a broad range of disciplines related to disabilities. Whether the focus is on leadership, direct service, clinical or other personnel preparation, these pre-service and continuing education programs are geared to the needs of students, fellows, and practicing professionals and have been essential in raising and defining the educational standards of services across health, education, employment and social service systems. Further, they have increased the capacity of States to be responsive to the needs of individuals with disabilities.

Each year, UCEDDs provide education and training to approximately 500,000 health, education, mental health, and policy-making professionals, as well as people with disabilities and their families. UCEDDs in communities nationwide provide this essential education and training.

For example, one issue that Centers focus on nationally is positive behavioral supports. *One UCEDD in Oregon houses the Center on Positive Behavioral Intervention and Support. The Center assists local schools in identifying, adapting, and sustaining effective behavioral practices, including school-wide discipline programs. Results from their replication efforts in over 400 schools nationwide indicate that their technical assistance and research has enhanced schools' capacity to address behavioral challenges, diminish disruptions, reclaim instructional time, and enhance quality and effectiveness of instruction.*

LEND programs provide training to advance the knowledge and skills of the full range of child health and allied health professionals to improve health care delivery systems for children with developmental disabilities. These programs provide health care professionals with high-quality interdisciplinary education that emphasizes the integration of services supported by State, local agencies, private providers and communities. Health professionals acquire the skills needed to foster a community-based partnership of health resources and community leadership and learn to promote innovative practice models that enhance cultural competency, partnerships among disciplines, and family-centered approaches to care. While these grants do not fully fund all necessary LEND faculty and trainees, they serve as a stable base from which programs can attract additional support from such sources as local, state and federal grants and contracts, fees for services and their universities. Increased financial support is necessary for these programs to expand the integral training, services, education and resources they provide and to meet the growing needs of children and families with special health care needs. In FY 2005, the most recent year that data is available for, LEND programs were able to provide this unique, intensive training to nearly 3,000 professionals.

Research – UCEDDs engage in cutting edge research on a wide variety of issues related to individuals with developmental disabilities and their families. From basic research to applied research and policy analysis, University Centers work to link research to public policy and professional practice. By studying areas such as brain development, autism spectrum disorders, and early literacy, UCEDD researchers are learning how children and adults learn and how best to teach and support them. UCEDDs lead in developing and

evaluating new ideas and promising practices that improve the lives of children and adults with disabilities and their families and increase their access to quality services. Many participate in federally established research projects to study and disseminate information on the causes and prevention of disabilities and chronic conditions. UCEDDs conducted more than 250 research projects totaling more than 87,000 hours worth of research in FY2005.

One example of how research policy and practice is a collaborative effort among Maine's UCEDD and the Maine state Departments of Education and Health and Human Services. Together we are studying the issues of access to, retention in, and indicators of high quality inclusive childcare for all children throughout the state. This multi-year, interdepartmental initiative is studying ways to develop a coordinated system of inclusive childcare and early education for all children, including those who are at risk due to poverty, disability, social-emotional and behavioral challenges, abuse, or language and cultural differences. By implementing and studying this issue, the UCEDD will be able to inform policymakers in areas such as staff development and retention of childcare staff, providing childcare support to TANF families, inclusive childcare support for children with disabilities, and supporting children in foster care.

Service – UCEDDs provide direct services and supports to people with developmental and other disabilities, their families, and communities, including state-of-the-art diagnosis, evaluation, and support services for children and adults with disabilities in health care, cognitive development, behavior disorders, education, daily living, and work skills. Moreover, through technical assistance to other providers, they magnify the impact of their programs, reducing disparities among individuals and communities. In just one year (FY 2005), UCEDDs provided direct or clinical services to nearly 90,000 individuals with developmental disabilities and/or their families.

One UCEDD is working with families living in rural counties of Ohio who encounter many barriers to accessing quality care for their children. Because most services for children with disabilities are in urban areas, families in Appalachia were traveling 100 miles to the city for multiple evaluations by individual disciplines. This resulted in a great expense in time and money for the family. The Center now sends teams of providers to rural areas to provide interdisciplinary care to families. They provide evaluation of children, training for local healthcare providers, and support for the families through a system of rural clinics. These clinics are improving access of needed services to families and providers and help local providers to better diagnose developmental disabilities such as cerebral palsy, fetal alcohol syndrome, autism and other genetic disorders.

UCEDDs also lead in improving the lives of people with disabilities through new technologies. More than 20 UCEDDs including those in Pennsylvania, Iowa, Texas, and Utah provide services that help individuals assess their technology needs and get the equipment they need to read, hear, speak, write, learn, work, play, and fully participate in their communities.

Responding to National Needs – UCEDDs are equipped to respond quickly to emerging national needs. We are currently expanding our work in the area of aging and disability. As we continue to see people with disabilities living longer, aging parents need community support to ensure the safety and well-being of their adult aged children with disabilities when they can no longer care for them and communities must be prepared. UCEDDs are working in communities on many aging-related projects and working with the White House Conference on Aging to ensure that aging and disability is part of the national dialogue.

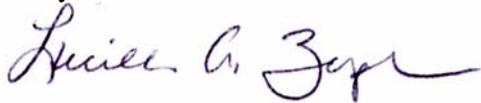
We continue to work with the federal government on policies and initiatives on emergency preparedness for people with developmental and other disabilities sharing much of our expertise and experience that came with the September 11 disaster and the response to Hurricane Katrina. For example, the New Mexico UCEDD developed a manual for first responders in how to deal with people with disabilities. The manual is being used and replicated in other states as they attempt to develop comprehensive plans to prepare for national and regional disasters. The Mississippi UCEDD is working with volunteer agencies to provide case managers and relocation services for victims and evacuees of hurricane Katrina throughout the state.

Another national issue that has been addressed by UCEDDs is treatment and diagnosis of autism and related spectrum disorders, a disability whose 805 percent increase in prevalence from 1992 and 2003 is systemic across the U.S. According to the Department of Education that tracks the number of students meeting the states' eligibility criteria for special education due to autism, the number of children with autism in 2003 was 163,773 (www.ideadata.org and www.cdc.gov/nchs).

I again ask that you consider our request for \$37 million the network of UCEDDs and \$22, 677,644 for LEND programs so that we may expand our network to more adequately serve the nation's growing population of Americans with developmental and related disabilities and to address our nation's health disparities.

Thank you for the opportunity to share this information about the UCEDDs and LEND programs. Your careful consideration of our appropriation requests is appreciated and we are happy to share more detailed information with you at your request.

Sincerely,



Lucille Zeph
President, AUCD